Adjustment and Intervention Needs in Young Carers of People with Chronic Illnesses or Disability: A Systematic Review

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Statement of Originality

I declare that this research report is my own work and that, to the best of my knowledge and belief, it does not contain material from published sources without proper acknowledgement, nor does it contain material which has been accepted for the award of any other higher degree or graduate diploma in any university.

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Sathya S Maniam 9 May 2018

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Abstract

The need for informal carers has significantly grown, and continues to grow, with young people under the age of 25 years taking on the carer role for people (usually family members) with chronic illnesses. On average young carers can provide up to 20 hours of various physically and emotionally demanding duties per week. This provision of care is often associated with psychological distress and an increased risk of having a chronic illness themselves. This reduces their capacity to manage their own needs and provide quality care to a chronically ill person. Young carers who are not adequately supported with appropriate psychosocial intervention represent an especially vulnerable population with developmental concerns particularly faced by adolescents. This systematic review identified and evaluated quantitative research, focusing on the outcome of psychosocial interventions on young carers of people with chronic illnesses. CINAHL via EBSCO, EMBASE via OVID, Medline via OVID, PsychINFO via OVID, PubMed, Scopus and Web of Science were the selected and searched databases. Unpublished/grey literature was noted in Scopus and the World Health Organisation database. The systematic search revealed that only 4 studies met the inclusion criteria to be included in this review. Assessment of scientific rigour and risk of bias revealed methodological limitations of the included studies and results indicate minimal intervention efficacy. This review emphasises the need for gaining further quantitative evidence on the efficacy of psychosocial interventions for young carers. Furthermore, there is a need to develop standardised protocols for age-appropriate interventions designed to promote psychosocial adjustment among young carers and assist in the development of governmental policies to better support these vulnerable individuals take better care of people with chronic illness.

Keywords: Young carers, Chronic illness, Disability, Psychosocial, Intervention

Adjustment and intervention needs in young carers of people with chronic illnesses or disability: A systematic review

Chronic physical and mental illnesses are the leading cause of disability and death worldwide. According to the World Health Organisation (2009), 75% of deaths in high-income nations are due to chronic illness or disease (WHO, 2009). Within Australia, 90% of deaths in 2011 were associated with chronic illness or disease (AIHW, 2014). Chronic illness including physical and mental disability that may never be cured and generally require long-term self-management, care from family members and healthcare providers (AIHW, 2014; Cummins et al., 2007).

An informal carer is usually a close friend or family member who may be unskilled and provide unpaid care to the person living with a chronic illness (Cunningham et al., 2016). Informal carers are instrumental in the realisation of home-based care and thereby delaying or preventing the need for institutionalised care for the person with a chronic illness. The informal care role is also expanding due to the cost of healthcare. This simply means that families with limited financial resources may have inadequate access to appropriate healthcare which subsequently results in family members or friends assuming the role of informal carers (Day, 2015; Pinquart & Sorensen, 2005). In Australia alone, it was estimated that if the informal carers in 2015 were replaced with formal care providers, it would have cost the national health system $60.3 billion with a varying replacement cost each year (Access Economics, 2015). The need for informal carers has significantly grown and continues to grow alongside the “global ageing” phenomena. In particular, due to increased life expectancy, there is now a greater number of individuals living longer with

chronic illness and disabilities (WHO, 2011; Hayutin, 2007). Many people with a chronic illness rely on the support of informal carers by incorporating family members or friends who they trust to promote, restore and maintain their health. Thus, it is critical that informal carers are adequately supported to ensure their capacity for caregiving can be sustained (Cummins et al., 2007).

Typically, the role of an informal carer is usually assumed by parents, spouses or adult children in mid-life (Cass et al., 2009). However, increasingly young people under the age of 25 years are taking on this role to care for unwell co-residing family members such as their siblings, parents, grandparents, or other residing family members (Cass et al., 2009). Although there are several definitions of a young carer, in Australia a young carer is commonly defined as an individual aged between 10 to 24 years who provides care to a family member with a chronic physical or mental illness or disability (Cass et al., 2009). According to the Australian Bureau of Statistics – ABS (2015), the proportion of Australians who are carers increases with age; from an estimated 10% of carers aged under 25 years to 20% of carers aged 55 to 64 years (ABS, 2015). However, the figure of young carers is projected to increase substantially in the coming years due to factors such as insufficient Commonwealth funded formal support services, an aging population, increases in sole-parent households, the rising prevalence of chronic illness and disability in our community, and young people assuming this role due to emotional necessity (ABS, 2014).

Young carers often undertake a range of core-domestic patient care (e.g. changing dressings/wound care), cognitive and emotional care (e.g. providing comfort), and intimate care (e.g. showering, toilet assistance) (Dearden & Becker, 2005). Young carers are also responsible for non-patient centred care activities (i.e. property management, household chores, meal

preparations, organizing transport and appointments) (ABS, 2015). In addition, young carers may also take on caring responsibilities for other family members within the household (e.g. younger siblings). On average, young carers provide between 10 to 20 hours of care per week to a loved one (Dearden & Becker, 2005), while attending their own educational, or occupational responsibilities alongside their role as a young carer. The responsibilities of care do not typify the standard responsibilities undertaken by individuals in this age group, where there is usually a greater focus on personal ambition, and transitioning to early adulthood and independence (Day, 2015).

Although research has identified positive outcomes associated with caregiving such as a sense of purpose and closer attachment with the recipient (Lloyd, 2013), informal caregiving has also found some adverse financial, emotional, psychological, social and physical effects on the caregiver (Cummins et al., 2007). The time taken to care for a family member can impact the carers ability to participate in personal self-care, their ability to cope with stressors, participate in employment, prioritise education and remain engaged in the community (ABS, 2015). Research has also shown that carers access healthcare services more frequently than non-carers due to psychological (e.g. stress, depression) and physical health complaints (Ali et al., 2014), with over one-third of primary carers (37.8%) living with a disability themselves as compared to non-carers (15.7%) (ABS, 2015). Furthermore, having impaired physical and psychological health due to caring has been shown to reduce individuals' quality of life and capacity to manage their own needs. This is a detriment to the carers health and their ability to provide quality care to family members living with a chronic illness (Gill et al., 2007).

While there is a growing body of literature exploring the effects of caregiving on the carer, the majority of research focuses on older carers with a scarcity of research focusing on young carers. The disparity in information between older carers and younger carers represents a critical gap in the literature (Day, 2015; Lloyd, 2013). Young carers face unique developmental challenges not typically associated with older carers and as such, the adverse effects of caregiving may manifest differently in areas of life functioning that are less relevant to older carers. For example, young carers are usually simultaneously undertaking educational study or training, however, due to caring duties, they often spend less time in school or completing homework compared to non-caregiving peers (Dearden & Becker, 2005). As a result of reduced or limited school, the young carer may subsequently face difficulties in skilled employment and/or future academic based endeavours (Day, 2015). Young carers also have lower employment rates compared to non-caregiving peers (Cunningham et al., 2016). Time spent caring can impact the young carers ability to routinely participate in employment which in turn influences their financial stability and reduce the household income (ABS, 2015).

The responsibilities of caring may also limit a young carers participation in social and recreational activities restricting their social development (Lloyd, 2013). As a result, the young carer may be more susceptible to experiencing a decline in their psychological well-being (Lloyd, 2013). Young carers also report having frequent physical injuries, chronic pain, severe levels of depression, low levels of happiness and often cannot afford medical treatment for themselves (Carers Australia, 2010). Experiencing prolonged maladjustment can place young carers at increased risk for sleep difficulties, self-harm and suicide (Cunningham et al., 2016). These risks are particularly concerning given that the leading cause of death among young Australians aged 5

to 17 is suicide, thus, young carers who are not adequately supported represent an especially vulnerable population (Carers Australia, 2010; Day, 2015). Long-term consequences can persist with young carers into their adulthood especially where there is reduced social support, positive peer friendships and self-efficacy, all of which are predictors of positive adjustment and independent identity (Cunningham et al., 2016; Currie et al., 2009; Newman, 2002).

Despite considerable research investigating the efficacy of interventions designed to promote older carer adjustment (e.g. psychological distress, coping skills, and quality of life; Acton & Kang, 2001; Candy et al., 2011), there appears little evidence of interventions specifically designed to meet the needs of young carers. This is in part due to the current lack of robust research investigating the impact of caregiving on young people (Day, 2015) which would be required to help inform the development of specialised and age-appropriate interventions designed to promote adjustment among young carers and assist in their role of providing quality care (Ali et al., 2014; Carers Australia, 2010).

This study aims to provide a systematic review of empirical research on young people providing care to someone with a chronic illness and/or disability. The specific objective of this review is to identify and investigate the efficacy of 'psychosocial intervention' for young carers caring for a person with a chronic illness. In doing this, it will also aim to establish the evidence base for both the impact and efficacy of the interventions on these carers. Identifying the intervention needs specific to young carers will help to inform intervention development and public policy to better support this growing cohort of young carers.

Method

Design

This study is a systematic review of existing research on the efficacy of the intervention on young carers of people with chronic illnesses or disability. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used (Moher et al., 2009).

Inclusion Criteria

Adhering to the Australian definition of a young carer, this review includes studies conducted with young carers between the ages of 10 to 26, and the aim of the study is to explore adjustment needs in this group of carers. While randomised control trials (RCTs) are recommended for evaluating the efficacy of interventions, in an area of relatively new research, it is expected that the evidence base will be minimal. Thus, non-randomised quasi-experimental studies were also included. Thus, included study designs were RCTs, quasi-experimental studies (i.e. waitlist control), non-randomised and single arm interventions. This review also assessed the evidence presented in grey literature including unpublished theses and dissertations from the World Health Organisation database.

Exclusion Criteria

Studies which were not published in English and those that did not focus on or report results specific to carers between the ages of 10 to 26 years were excluded.

Databases & Search Parameters

Studies were identified from computerised searches using CINAHL via EBSCO,

EMBASE via OVID, Medline via OVID, PsychINFO via OVID, PubMed, Scopus and Web of Science. A search for unpublished/grey studies using databases including, Scopus and the World Health Organisation was also conducted.

The search terms used were:

(young carer* OR young caregiv* OR young informal carer* OR youth carer* OR youth caregiv* OR Youth-caregiv* OR adolescen* caregiv* OR young adult carer* OR young adult caregiv*)

Analysis

All titles, abstracts, and keywords were reviewed and evaluated against the inclusion criteria independently by the first author. Post data search, duplicates were removed through Endnote X8 and through manual search. The remaining articles were initially screened by title, followed by a second screening by the abstract. Studies that were identified as potentially meeting the inclusion criteria were reviewed by reading full texts in the third screening against the inclusion/exclusion criteria. Any studies with an uncertainty of inclusion were reviewed by two reviewers (S.M and J.S) until consensus was reached.

Data Extraction

Data from included studies were extracted independently using a data extracted tool developed for this study based on the inclusion and exclusion criteria (Appendix C). The data extracted comprised of specific information and details about the included study design, studies methods, participant demographics, interventions, outcome variables, outcome measures and methods of statistical analysis. For studies that did not report effect size or reliable change index,

calculations were done using the provided information in the study to evaluate the magnitude and strength of the intervention.

Risk of Bias

Quality of research and assessment for risk of bias was also examined against CONSORT for RCTs (Moher et al., 2010, Altman et al., 2001) and the Revised Cochrane Risk of Bias Tool for randomised trials (RoB 2.0) for RCTs (Higgins et al., 2011). The Risk of Bias in Non-Randomised Studies – of Interventions (ROBINS-I) assessment tool was used to non-randomised designs (Sterne et al., 2016). Risk of bias was evaluated independently by S.M and uncertainties were resolved through seeking additional clarification from M.Q until consensus was reached.

Results

Figure 1 depicts the data extraction process where studies were screened, assessed for eligibility, and included in this review. The search yielded 12,486 studies of which 1587 were duplicates. Once duplicates were removed, the titles of the remaining 10,899 studies were screened to eliminate studies that did not meet the inclusion criteria which led to the elimination of 10,792 studies. From the remaining 107 studies, abstracts were screened which led to the exclusion of 63 studies. Finally, full-text of the remaining 44 studies were reviewed to determine if the studies met the current reviews inclusion criteria. The full-text screening resulted in the exclusion of 37 studies. Double checking was performed on three full-text studies to determine consensus on their eligibility; this was completed by two reviewers (S.M and J.S). This resulted in the exclusion of all three studies. The process of inclusion led to four studies being deemed eligible against the inclusion criteria for this review

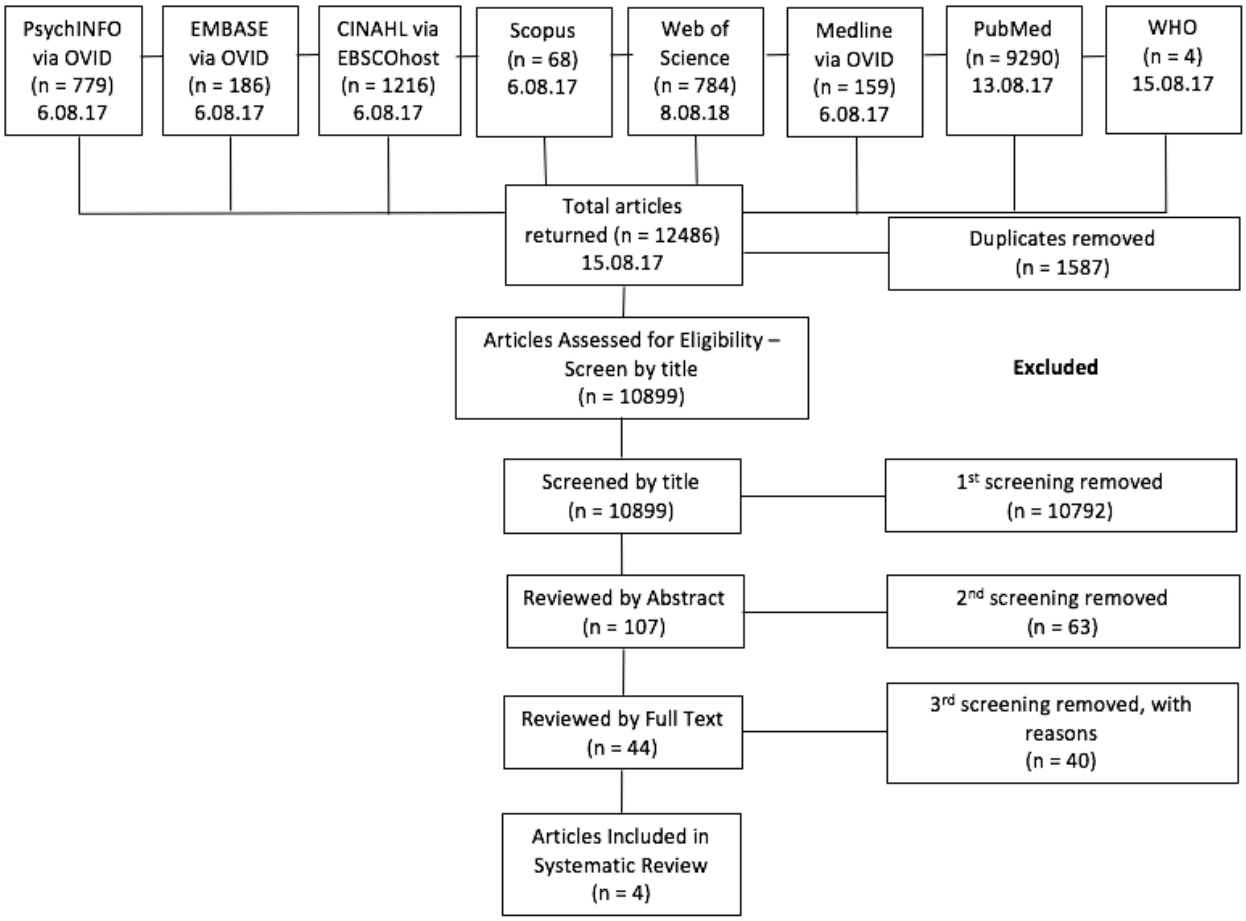

Figure 1. Flowchart of study selection for this systematic review. Adapted from PRISMA.

A large proportion of studies were excluded due to the focus on parents as carers, studies that employed qualitative, survey, and cross-sectional methodology. Full-text review of the remaining 44 that were deemed to possibly meet the inclusion criteria based on screening of the title, resulted in 20 exclusions because the studies focused on carers aged above 18 years, with the majority of carers above 26 years. A further five studies were excluded because they were noted to be 'feasibility of intervention pilot studies'; whilst a further four studies were not intervention studies. Full-text articles could not be obtained for three studies, because they were unpublished grey literature, a conference poster abstract and a letter to an editor. Two studies were not published

in English, two studies included parents who are caregivers, followed by one study that did not report the caregiver's age. Finally, two meta-analyses, one systematic review and a qualitative study were all excluded. Refer to Appendix A for a list of studies that were excluded after reading the full-text, with reasons of exclusion.

Following the filtering and exclusion process, four studies met the inclusion criteria, two of which are RCT studies, one wait-list control study, and one single-group longitudinal intervention study. Given the small number of RCTs located, and the range of outcome measures used, it was not feasible to conduct a meta-analysis.

Both Table 1 and Table 2 are presented on subsequent pages. Table 1 summarises the characteristics of the two RCT studies, one wait-list control study, and a single- group study employing quantitative methods to explore the effectiveness of interventions in young carers. While Table 2 summarises the Cohen's d effect size for the outcomes relevant to this review followed by the questionnaires utilised.

Table 1

Summary of Control-Trial Evaluations of Interventions Efficacy on Young Carers

Study	Participants & Design: (n) Age range [% of yc]	Participants & Design: n, Condition	Participants & Design: Parental illness	Follow-up/End-point	N, Session (*f*), length (duration)	Treatment: Format (components)
Randomised Controlled Trials (RCTs)						
Ali, Krevers, Sjostrom, & Skarsater, (2014)	(241) 16-25 yrs [100%]	1. 1, INT 2. 1, C	NR Studies inclusion: -Long-term illness -MH problems (NS) -Disabled -Conditions that require support	8 months	NR (dependent on how often participants access the site)	1. Online (S-C, info on where to get help, MH info, blog, forums, links) 2. Folder resource (24 different SS, links, PN)
Leavey et al., (2004)	(88) 16-25 yrs [51.8%]	1. 1, INT & SC 2. 1, SC	PI	9 months	7 x 1hr (NR)	1. SC & BI (IG, PI edu, CS, PS, COMS, info pack with PN and SG) 2. SC from psychiatric services
Wait-list Control Trials (WLC)						
Fraser & Pakenham, (2008)	(44) 12-17 yrs [100%]	1. 1, INT 2. 1, WLC	-Depressive disorder -Bipolar -Anxiety disorder - Psychosis/Schizophrenia -Drug abuse/Dependence -Personality disorder -Eating disorder	8 weeks	3 x 6hrs (fortnightly)	1. Group program (PsyEd on MI, CS, peer support, GD, quizzes, other recreational activities)
Single-group Studies						
Coles, Pakenham, & Leech, (2007)	(20) 9-14 yrs [100%]	1, INT 0, C	MS	3 months	2 groups 8 x 1-2hrs (6 days)	1. Camp group (CBT PsyEd, CR, COMS, quiz, GD, MS edu, social support, RP, PS, EFC, PMR, deep breathing, visualisation techniques)

Note. (S-C) self-care, (MH) mental health, (SS) support services, (PN) phone numbers, (PI) psychotic illnesses, (edu) education, (IG) information gathering, (PS) problem solving, (COMS) communication skills, (CS) coping strategies, (SG) support group), (PsyEd) psychoeducation, (MI) mental illness, (MS) multiple sclerosis, (CBT) cognitive behavioural therapy, (CR) cognitive restructuring, (GD) group discussion, (RP) roleplay, (EFC) emotion-focused coping, (BI) brief intervention, (NS) not specified, (NR) not reported.

Table 2

Summary of Cohen's d Effect Size Outcome

Study	Outcome Questionnaires utilised				
	Stress	QoL	Burden/ strain	Psych Adj (depression)	Satisfaction
Randomised Controlled Trials (RCTs)					
Ali, Krevers, Sjostrom, & Skarsater, (2014)	{-0.02 = almost small} *25.1* (9.6) Perceived Stress Scale (PSS)	-	-	-	-
Leavey et al., (2004)	-	-	^ Caregiver Strain Index (CSI)	-	-
Wait-list Control Trials (WLC)					
Fraser & Pakenham, (2008)	{0.0699 – 0.2552 = small} Response to Stress Questionnaire – Family Stress Version	-	-	{0.3558 = small} Children's Depression Inventory-Short Form	{-0.1774 = small} five-item Satisfaction with Life Scale
Single-group Studies					
Coles, Pakenham, & Leech, (2007)	-	-	-	#0.01 Brief Symptom Inventory-18	#-0.08 five-item Satisfaction with Life Scale

Note. Cohen's d{effect size} between treatment and control groups at post measurement for RCT and WLC only. (#) reliable change index (RCI) (≥1.96 significant) between groups at post measurement was calculated for only the single-group study. (n) number, *M*(SD), mean (standard deviation), (^) unable to calculate effect size or RCI, (-) indicate outcome not measured, (C) no-treatment control, (INT) intervention, (SC) standard care control, (QoL) Quality of life, (YC) young carer.

Ali, Krevers, Sjostrom, and Skarsater (2014) compared the impact of two intervention groups through a randomised controlled trial design. Participants aged 16 to 25 (Table 1) were recruited in Sweden and allocated randomly into either a web-based intervention or a 'folder' group. The web-based group was provided online access to resources, online blog interactions with professionals, whilst the folder group was provided printed material of useful information on 24 different community support services. Authors noted the participants who accessed the online material in the intervention group, on a flow chart, however, summary statistics to indicate frequency and duration of access and interaction with professionals were not reported. Authors did not report if participants in the folder group accessed any of those community services.

Results were calculated based on the number of participants intended to treat (120 Web-group, 121 folder-group) as opposed to the number of participants who accessed (participated in the intervention) the resources. According to the presented flowchart, it is evident that less than 35% of web-group participants accessed the material at each analysis point (i.e. baseline, 4 months, 8 months; Ali, Krevers, Sjostrom, & Skarsater, 2014).

The research did not find a significant difference in stress between groups. However, the folder group despite having a higher mean at baseline had a trend that declined in the participant's stress over time. According to findings, both groups did not report any significant difference, and yielded small effect sizes (reviewer calculated) at post treatment and follow up. The quality of support for intervention as compared to the control group was also found to have a negative medium effect size (d = -0.53) at the four months follow up. This indicates that with intervention, young carers were better at taking care of their chronically ill family member.

However, these gains were not maintained at the 8 months follow up. Results of this study do not support that the intervention was effective.

To ascertain the quality and assess the scientific rigour of the study, the Risk of Bias (ROB) tool developed by Higgins et al. (2011) was utilised. Table 3 highlights the results of the six main domains and provides an overall judgement of the study. As identified, there are 'some concerns' with the deviations from intended interventions, measurement of outcome, and the overall bias.

Leavey et al. (2004) explored the impact of a brief intervention on carers of patients after their first episode of psychosis. This RCT included both older carers and young carers in the trial (31 treatment, 24 control). Participants were allocated through block randomisation which ensures equal or close to equal sample sizes (Suresh, 2011). The intervention involved information gathering from carers, education on symptoms, early warning signs, treatment, and help-seeking. The intervention also included coping strategies, problem-solving and learning to communicate with the patient over 7 (1 hour) at home sessions. Carers were also provided with a carer pack of information about psychotic illnesses, addresses and telephone numbers of services and support groups, and were allowed to continue receiving usual care from the psychiatric services (Leavey et al., 2004). The intervention was designed to take into account carers cultural issues, how they conceptualise illness and difficulties in providing care. This was taken into account, as a majority of the participants in this study were largely ethnic minority and refugees. Authors reported that the control group maintained their usual support from psychiatric services, community mental health teams which did not follow a set protocol. However, a summary table describing the frequency of attending usual support, the type of support attended, and duration of support received were not provided.

Results indicated that there was not a statistically significant difference in carers' perception of the illness between groups over time. However, there was a lack of statistical information provided in the text. The effect size between the group was unable to be calculated by the reviewer as the means, standard deviations and the second degrees of freedom (df) value were not provided. Authors indicated a high number of participant refusal in the study and a high dropout rate which may impact the internal validity, the effectiveness of the intervention and increase the possibility of a type II error.

The Risk of Bias (ROB) tool (Table 3) indicates that there are 'some concerns' with the deviations from intended interventions, missing outcome data, selection of the reported data, and the overall bias. Although this RCT did not report following the CONSORT guidelines (as CONSORT was released a year after the research), to assist with blindness, researchers were instructed to avoid any discussion with carers about the support they received, and carers were requested not to discuss their care issues with the researchers.

The wait-list control and single-group study have a common author (Pakenham). Both these studies were conducted in Australia and included face-to-face group intervention. Fraser & Pakenham (2008) employed a quasi-experimental design with a wait-list control group. Authors indicated that participants were not randomly allocated into groups. Participant (27 treatment, 17 control) were recruited through the Koping Adolescent Group Program (KAP), with referrals made from Child and Youth Mental Health Services, and various community services. Participants who were on the KAP waitlist were allocated into the control group which lacks blindness between participant allocation into groups. This is a common drawback with waitlist control trials (Cunningham, Kypri, & McCambridge, 2013). Efficacy of the intervention may be impacted due to the lack of blindness and participants in the control group may already

have an interest in improving their mental health. They may have also received other support during the course of the study however, this was not assessed by the authors.

Several validated outcome measures were utilised (Table 1). Authors reported that mental health literacy was assessed using three open-ended questions on a five-point Likert scale and the questionnaire was developed by the first author with no reported validity or reliability information.

Results of the study indicate that both the treatment and control group changed at a similar rate over time. Authors of this study reported both significant differences $p < 0.05$, and reliable change index of pre-post treatment between groups. Overall, results failed to show statistically significant intervention effects. According to the reviewer calculated effect size, there were no differences between the treatment and control group except for medium-large effect size improvement in mental health knowledge, peer problem, and caregiving compulsion favouring treatment. The lack of effect between groups may be due to small sample size, and knowledge of being on a waitlist. Findings of this study suggest that the KAP program may decrease some caregiving impacts of young carers, however, a larger sample size is needed for future research to evaluate the effect and efficacy of the intervention.

To ascertain the quality and assess the scientific rigour of the study, the Risk of Bias in Non-Randomised Studies of Interventions (ROBINS-1) tool developed by Sterne et al. (2016) was utilised. Table 4 highlights results of the seven main domains and provides an overall judgement of ‘moderate bias’.

Coles & Pakenham (2007) employed a single-group design which only measures the intervention effects of a single group over time without a comparison group. The absence of a comparison group presents an added challenge in identifying confounding factors that may impact the effectiveness of the intervention. This further impacts the study's generalisability. The intervention involved a six-day residential camp program for children. It involved a total of eight one-two hours' group sessions incorporating cognitive-behavioural psychoeducational approach, education about multiple sclerosis (MS), emotion-focused coping strategies, communication skills, problem-solving, relaxation, and life skills.

Twenty participants aged 9 to 14 completed several questionnaires at pre-post and follow-up. Several of the questionnaires were developed for the purpose of the study (i.e. knowledge of MS, coping strategies, communication skills, and adjustment). Authors reported that they were unable to acquire suitable questionnaires for the purpose of their research. However, other scales measuring coping strategies, caregiving impact, family cohesion and family conflict, benefit finding, distress, positive effect, and satisfaction with life had good reliability and validity. Authors reported significant changes among several results however, the reviewer calculated 'reliable change index' (RCI) reveal all measures showed an RCI<1.96, indicating no reliable change post treatment. Based on the (ROBINS-1) overall scientific rigour of the study indicate 'serious bias' (Table 4). The methodological problems impact the reliability of the study, however, this study demonstrates that the concept of developing a group program for children is feasible for future studies.

Table 3

Risk of Bias-2 (ROB-2)

Study	Randomisation process	Deviations from the intended Intervention	Missing outcome date	Measurements of the outcome	Selection of the reported results	Overall Bias
Ali et al, 2013	Low	Some concerns	Low	Some concerns	Low	Some concerns
Leavey et al., 2004	Low	Some concerns	Some concerns	Low	Some concerns	Some concerns

Table 4

Risk of bias for non-randomised studies-1 (ROBINS-1)

Study	Bias due to confounding	Bias in the selection of participants into the study	Bias in the classification of intervention	Bias due to deviations from intended interventions	Bias due to missing data	Bias in the measurements of outcomes	Bias in selection of the reported results	Overall bias
Fraser & Pakenham, 2008	Moderate	Low	Low	Low-Mod	Low	Moderate – Serious	Low	Moderate
Coles, Pakenham & Leech, 2007	Serious	Low	Moderate	Low	Moderate	Serious	Low	Serious

Discussion

The aim of this systematic review was to investigate the efficacy of 'psychosocial intervention' on young carers of people with chronic illness and disability. Despite the wealth of information on the effectiveness of interventions on carers, little is known about effective intervention for young carers as there still appears to be a gap in the literature (Thomas et al., 2017). According to the ABS (2016), the number of young carers is predicted to increase. Despite this pressing need and importance of understanding ways to provide intervention for young carers, only a small number of heterogeneous studies were identified which met the inclusion criteria for this review. When reviewed systematically, scientific study in the area of young carers is limited to two RCTs, one WLC trial, and a single-group study. The pattern of results across the reviewed studies indicated that there were minimal effects to young carers when treatment was provided. These results are useful in adding to a small pool of knowledge, however, variability in the reviewed studies methods warrant discussion due to the impacts of reliability and generalisability of their findings. The limitations of the included studies, as well as of the current review, shall be considered prior to exploring the implications of the current reviews results.

The studies included in this review used various platforms for intervention. The protocols employed different formats of intervention delivery and availability or provided a varied number of sessions. The platform or mode of delivery for intervention components lacks standardisation with diversity in the intervention which potentially impacts the outcomes measured. The age of the participants may also influence young carer outcomes, as developmental and biopsychosocial factors influencing their capacity to provide care can impact the young carer. Each of the included studies had carers of different age ranges. Ali et al (2013) and Leavey et al (2004) included young adults into their RCTs, while the remaining two studies

only had adolescents. Time effects across the included studies also varied, with only two studies assessing intervention effects beyond six months after the intervention, hindering information and understanding of long-term or delayed effects of providing interventions.

Methodological issues in the study

The methodological quality of the included studies indicated a moderate risk of bias for three studies and serious risk of bias for one (Table 3 & 4). Overall concerns with the included studies exhibit a lack of randomisation, blindness, small sample sizes and limited outcome information provided. For example, all the studies reported statistical significance and failed to report effect sizes; which would have been beneficial in understanding the effectiveness and magnitude of change caused by the intervention. These studies did not provide information on the patient's stage of illness or the carers level of investment in caregiving tasks that contribute to their young carer role. Although the intervention study conducted by Ali et al (2013) identified their study as a randomised controlled trial, once the participants were allocated to their groups, involvement in the group was dependant on the participant, thus impacting the ability to draw precise conclusions.

Reasons for limited efficacy of studies

There are several factors that may have contributed to the small effects in all the included studies. These include small sample sizes and high dropout rates (noted in three studies), which indicates that they had low power to detect intervention effects. Although reasons for drop out were not reported, it is possible that carers with a mental illness or disability themselves are more likely to drop out of the study as participating may contribute to limited time spent managing their own health, thereby, lessening the effects of the intervention on carers outcome. According to the ABS (2015), a third of carers are living with a form of disability themselves

(ABS, 2015) which may impact their caretaking abilities, and willingness to continue participation. Due to the nature of the participants as adolescents with multiple duties, most studies predicted high dropout rates as seen in both the RCT studies. Although it was hypothesised by Ali et al (2013) that adolescents may access online resources when provided access to useful resources, this study identified that only a quarter of participants accessed these resources. The lack of engagement in the intervention may have also impacted the effect size of the intervention. Finally, other factors such as the carers awareness that chronic illness cannot be cured or stopped from progressing and may remain as an ongoing stressor could have also contributed to the limited efficacy of the intervention. Overall, this review found that the quality of evidence on intervention efficacy on psychosocial outcomes among young carers was mediocre and should be interpreted with caution.

Limitations of the current review

The systematic literature search was limited to studies that were written or translated into English. Therefore, there is a possibility that not all quantitative intervention studies conducted on young carers were included in this review. Furthermore, due to the use of one reviewer for most of the screening, there is a possibility that some possible studies may not have been included in this review. Limitations of the included studies comprised of small samples of young carers, and these studies mainly focused on family members with a mental illness. Understanding of other chronic illness and disability were not identified from the included studies.

Implications of this review, and future directions

This review draws awareness onto the role young people have as carers for family members with chronic illnesses, and the lack of evidence-based interventions to assist their

functioning. There is a general consensus in the literature that there is a gap in the efficacy of interventions for young carers, and based on this review such concerns are warranted. When young carers needs are not addressed, their physical and mental health is at risk, which may ultimately impact the patients from receiving optimal care (Northouse et al, 2010).

According to the general literature, it is evident that the amount of domestic care is likely to increase with age, as the carers are able to endure physically demanding tasks, however, the amount of emotional caregiving is similar across carers of all ages (Dearden & Becker, 2004). Caring at a young age can interfere with the young person's development and as a result restricts their ability to partake in social and emotional activities which are important in improving health, well-being, and resilience (ABS, 2015; Pakenham et al., 2006). Children who adjust better to parental illness have social support, coping skills (i.e. problem-solving, seeking acceptance and support), lower stress, and display less avoidant coping (i.e. denial, wishful thinking) (Pakenham et al., 2007). Future research should consider interventions that build on these capacities to enhance young carers resilience (Parrott et al, 2008; Roberts et al, 2008) and provide intervention for physical and emotional caregiving.

In general, this review shows there is a lack of quantitative intervention studies on young carers of people with chronic illnesses. Despite the wealth of research evidence in the carer literature showing the need for intervention studies on young carers, little is known about the efficacy of interventions in this population. There is a need for well-funded high-quality RCT studies, with larger sample sizes, long-term post-intervention follow-ups, with a greater ability to detect intervention efficacy and generalise findings. High-quality quantitative studies will improve knowledge about meeting young carers needs through efficacious interventions. Finally, given the demands of adolescence and risk of illness and disability in this population,

there is a need to consider the clinical significance of interventions targeting young carers who may not access services due to low SES, cultural circumstances, low-income families, and migrant/ linguistically diverse carers. Incorporating them will help increase their access to services and supports provided in the community (Cass et al., 2009). The lack of rigorous and consistent theoretical basis for intervention efficacy in young carers promotes difficulties to develop appropriate policies, interventions and professional development in this area.

Providing information and resources online may be useful to young carers who access the material as identified by Ali et al. (2014), however, there is a need for delivering effective evidence-based intervention through the use of technology. Advantages of interventions delivered via technology include convenience, increased accessibility, reduced cost, and efficacy in reducing carer depression (Scott et al., 2016). Future research should consider this mode of intervention delivery as it may be suitable for this carer population (Northouse et al, 2010).

Conclusion

In summary, through scoping the literature, the findings of this systematic review indicate that interventions were not found to be effective in reducing young caregiver's psychosocial outcomes. However, it is important to note that the paucity of evidence impacts the ability to draw a precise conclusion. This review highlights the need for more research and intervention to be developed, tested, and included in the database of efficacious evidence-based interventions for young carers.

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Appendix A

Summary of studies excluded from the review

Study number	Citation	Study type (journal article, book etc)	Study design (quant/qual)	Reason for exclusion
1.	(Ali, Ahlstrom, Krevers, Sjostrom, & Skarsater, 2013)	Journal article	Mixed-method Cross-sectional	• Explores how young informal carers experience the use of support. • Not a pre-post intervention study, no randomisation
2.	(Barrera-Ortiz, Pinto-Afanador, & Sanchez-Herrera, 2006)	N/A	N/A	• This study is not in English.
3.	(Berwig et al., 2017)	Study protocol	Randomised controlled trial	• Informal caregivers aged ≥18 years
4.	(Broning et al., 2012)	Study protocol	Randomised controlled trial	• Intervention study evaluating the effectiveness of a group program for children between ages 8 – 12 of parents with substance use disorder
5.	(Bulut, Arslantas, & Ferhan Dereboy, 2016)	Journal article	Quasi-experimental	• Carers aged between 18-75 years
6.	(Chatterjee et al., 2014)	Journal article	Randomised controlled trial	• Study participants included schizophrenic patients and their informal caregivers (caregivers age not provided)
7.	(Chien, Chiu, Lam, & Ip, 2006)	Journal article	Quasi-experimental	• <30% (22%) of carers were between 18-29. • Critically ill patients in ICU

8.	(Chien, Thompson, Lubman, & McCann, 2016)	Journal article	Randomised controlled trial	• Caregivers aged ≥18 years • Caregivers aged 20-29 were <30%
9.	(Collinge et al., 2013)	Journal article	Randomised controlled trial	• Caregivers mean age 51.5 years
10.	(Fortune, Rogan, & Richards, 2016)	Journal article	Wait-list controlled	• Caregivers mean age >52 years
11.	(Fung & Chien, 2002)	Journal article	Experimental	• Caregivers aged 18-30 were <30%
12.	(Gettings, Franco, & Santosh, 2015)	Journal article	Longitudinal Pre-post intervention	• Children's role was not specified by the authors • Feasibility of intervention study
13.	(Grover et al., 2011)	Journal article	Pre-post intervention	• Carers mean age is 50 years
14.	(Hager, Breslin, Treuth, & Black, 2005)	N/A	N/A	• Caregivers mean age is 39.5 years • Looks at the impact of caregiver support on adolescent's physical activity • Incomplete article (only abstract)
15.	(Halkett et al., 2015)	Journal article	Randomised controlled trial	• Carers aged ≥18 years
16.	(Hassan & Das, 2012)	N/A	N/A	• Letter to the editor
17.	(Hildebrandt & Cannan, 1985)	Journal article	Observation	• Caregivers were parents of children
18.	(Hornung, Holle, Schulze Monking, Klingberg, &	N/A	N/A	• Study is not published in English

	Buchkremer, 1995)			
19.	(Hudson et al., 2012)	Journal article	Pre-post intervention	• Caregivers mean age is 57.1 years
20.	(Hung, Liu, Hung, & Kuo, 2003)	Journal article	Randomised controlled trial	• Caregivers aged ≤24 were <30%
21.	(Hutchison et al., 2011)	Journal article	Pre-post intervention	• Caregivers median age is 52 years
22.	(Judge, 2011)	Conference poster abstract	Intervention study	• Conference poster abstract • Unable to locate published study • Early intervention program
23.	(Kate, Grover, Kulhara, & Nehra, 2013)	Journal article	Cross section	• Cross sectional study design, not an intervention study • Caregivers mean age is 45.9 years
24.	(Krieger, Feron, & Dorant, 2017)	Journal article	QUAL-qual mixed-method	• Caregivers median age is 62 years.
25.	(Kurz et al., 2016)	Journal article	Randomised unblinded design Wait-list control	• Program design and methods of a pilot study
26.	(Lobban et al., 2013)	Journal article	Randomised controlled trial	• Participants are young people experiencing psychotic symptoms • The age range of carers unspecified • Feasibility of intervention study
27.	(McCann, Songprakun, & Stephenson, 2015)	Journal article	Parallel group randomised controlled trial	• Caregivers mean age is 41 years • Age range not provided
28.	(Metzing-Blau)	N/A	Randomised intervention	• Grey literature from WHO

				• The recruitment status of this study unknown. The completion date has been passed and the status has not been verified in more than two years.
29.	(Northouse et al., 2013)	Journal article	Meta-analysis of randomised trials	• Meta-analysis of interventions with family caregivers of cancer patients • Not an intervention study • 29 studies included in the meta-analysis - caregivers age were above 26 years
30.	(Northouse, Katapodi, Song, Zhang, & Mood, 2010)	Journal article	Randomised controlled trial	• Caregivers were eligible if aged ≥18 years • Caregiver mean age is 56.7 years
31.	(Pakenham & Burnsnall, 2006)	Journal article	Cross section Questionnaire survey methodology	• Not an intervention study
32.	(Petrakis, Oxley, & Bloom, 2013)	Journal article	Intervention pre-post	• Carers above 30 years
33.	(Pomeroy, Rubin, & Walker, 1996)	Journal article	Evaluation article/study	• Carers age range is 18-68 years • No pre-post measures • Not an intervention study
34.	(Sieh & Visser-Meily, 2017)	Book chapter	N/A	• Book chapter • Not a quantitative study
35.	(Sin, Jordan, Barley, Henderson, & Norman, 2015)	Journal article	Systematic review	• Not an intervention study
36.	(Siskowski & Gwyther, 2013)	Book	Literature review	• Book chapter • Not an intervention study

37.	(Thomas, Dalton, Harden, Eastwood, & Parker, 2017)	Journal article	Meta-analysis	• Meta-review on support for carers • Not an intervention study
38.	(Valdez, Padilla, Moore, & Magana, 2013)	Journal article	Pilot study	• Children as caregivers not specified • Feasibility of intervention study
39.	(Whitney, Currin, Murray, & Treasure, 2012)	Journal article	Qualitative methodology	• Qualitative study
40.	(Wilkinson, Harris, Kelvin, Dubicka, & Goodyer, 2013)	Journal article	Randomised controlled trial	• Parents are referred to as the carer or caregiver of adolescents with depression • Parents also have mental illnesses

Appendix B

References of Excluded Studies

ADDIN EN.REFLIST Ali, L., Ahlstrom, B. H., Krevers, B., Sjostrom, N., & Skarsater, I. (2013). Support for young informal carers of persons with mental illness: A mixed-method study. *Issues in Mental Health Nursing, 34*(8), 611-618. doi:http://dx.doi.org/10.3109/01612840.2013.791736

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Appendix C

Data Extraction Forms

DATA EXTRACTION	
QUANTITATIVE	
Review question	identify and investigate the efficacy of psychosocial interventions for young carers
Inclusion: PICO	
Population	Patient population – Chronic illness, terminal illness, chronic disability, lifelong mental illness Carer population - Young carers aged 10-26, &/or ≥ 30% of the population in the study is aged 10-26
Intervention	Psychosocial intervention for young carers
Comparator	Anything alternative to the intervention group
Outcomes	Efficacy of intervention
Study design	RCT, quasi-experimental, single-arm qualitative with at least 1 outcome measures

DATA EXTRACTION INCLUDED STUDIES							
Reviewer name:				**Date of review:**			
Authors/Study ID:		**Study Title:**		**Year:**	**Journal:**		
Study Design:	☐ RCT Number of Intervention groups ☐ one ☐ two: _____ _____ _____	☐ Quasi - exp Non- Randomised trial.	☐ Cross over RCT	☐ Waitlist group ☐ Non Active Control Group ☐ 2nd intervention ☐ attentional placebo			
Aim of Study:							

		Intervention group (n)	Control group (n)	Total sample (n)	Not Reported (NR) ☒	Comments/ Notes:	Page no.
Participants	Number of participants				☐		
	Mean age (SD)				☐		
	Gender (n), %				☐		
	Ethnicity (n) %				☐		
	Birth order				☐		
	Illness caring for				☐		
	Education level				☐		
	Employment status				☐		
	Benefits (e.g. carers benefits, unemployment benefits)				☐		
	Mean income				☐		
		Intervention group (n)	**Control group (n)**	**Total sample (n)**	**Not Reported (NR) ☒**	**Comments/ Notes:**	**Page no.**

	Time spent caring (hours)				☐		
	Duration of care (months)				☐		
	Relationship to care recipient ☐ Mother ☐ Father ☐ Brother ☐ Sister ☐ Grandmother ☐ Grandfather Other:_____ _____				☐		
Study setting	☐ Urban				☐		
	☐ Rural						
	☐ Remote						

					Not Reported (NR) ☒	Comments/ Notes:	Page no.
Intervention details	Aim of intervention				☐		
	Intervention name				☐		
	Therapeutic type				☐		
	Intervention delivery/mode	☐ Face to face ☐ Online ☐ Telephone support	☐ Other _____		☐		
	Who delivered the intervention?				☐		
	What was their training/qualification?				☐		
	Number of session				☐		
	Duration of each session				☐		
	Frequency of sessions				☐		
	Duration of intervention				☐		

	Number of assessments (Ax)	☐ Pre Ax: _____	☐ Post Ax duration after intervention: _____ ☐ 3 months ☐ 6 months ☐ 9 months ☐ 12 months	☐ End point: _____	☐		
Questionnaires	**Name**		**Year & version**	**Validity**	**Alpha Cronbach**	**Psychometrics**	

		Not Reported (NR) ☒	Comments/ Notes:	Page no.
Primary Outcome		☐		
Secondary Outcome		☐		

INTERVENTION GROUP		Pre			Post			3 months		
	Measures	Mean	SD	N	Mean	SD	N	Mean	SD	N
Outcome										
		6 months			9 months			12 months		
	Measures	Mean	SD	N	Mean	SD	N	Mean	SD	N
Outcome										

CONTROL GROUP		Pre			Post			3 months		
	Measures	Mean	SD	N	Mean	SD	N	Mean	SD	N
Outcome										
		6 months			9 months			12 months		
	Measures	Mean	SD	N	Mean	SD	N	Mean	SD	N
Outcome										

TOTAL Treatment Vs Control		Pre		Post		3 months	
	Measures	**Effect Size (Cohen d)**		**Effect Size**		**Effect Size**	
Outcome							
		6 months		**9 months**		**12 months**	
	Measures	**Effect Size**		**Effect Size**		**Effect Size**	
Outcome							
Effect Size	☐ Author reported	☐ Reviewer calculated		Statistical significance? Reliable change index			